

Voices of People Living With HIV/AIDS



New Light

AIDS

Control Society

Acknowledgement

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"All of you sit on the floor. Do not dare to sit on the seats", scolded the ambulance driver, to the handcuffed family of Nazir Masih, while taking them to health department for mandatory testing for HIV. The government ambulance and the police came with screaming sirens and screeching brakes to the front door of Nazir's house. The whole street shook up. The year was 1992. It marked the beginning of a long nightmare. "Despite having been deported from UAE in 1990 because of my HIV status, and worrying everyday about what will happen to my family after I am no more, that was the worst day of my life", recalls Nazir. Humiliated and overwhelmed by the guilt of dragging his family into this situation, he felt helpless as a father who could not reassure his children huddled together on the floor of the ambulance, looking at him for answers.

Living in a house arrest of sorts, Nazir welcomed into his home four months later, two gentlemen from a national newspaper posing as government health officers. The family was interviewed, photographed and the next morning, papers all across the country carried the news and information on the whereabouts of Nazir and his family. The whole world knew what Nazir had been desperately trying to keep to his family, until that day.

Then in the same year, he met Professor Dr. Rasheed, an angel in disguise, handling HIV testing at the Institute of Public Health, Lahore. He was very supportive and friendly to Nazir.

Angel and Phoenix





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One day he said, "Nazir, you should declare your HIV status to the public. The cat is already out of the bag, by daring to reveal yourself you will conquer your own fears." That is what Nazir did. He was the first one in Pakistan to openly declare his HIV status. He felt he was a free man. A heavy load was off his shoulders. "Now you have to help other 'positive' people", said Dr. Rasheed plainly, putting the burden back on Nazir. "What? I cannot write and I can barely read," replied the bewildered Nazir, "All I know is how to fix broken down bicycles, so that people can ride again". Professor Rasheed smiled back, "Exactly".

In March 1999, New Light AIDS Control Society had a humble beginning in a bicycle repair shop. Slowly but surely people living with HIV started flocking to this little cycle workshop, for 'repairs'. Nazir's family backed him up wholeheartedly. Caring for PLWHA was a family business. 'Customers' shed their pains, shared their problems and got love in exchange. Nazir and his family faced and braced all kinds of attitudes from healthcare authorities, professionals, media and society, yet they remained steadfast in their mission. International NGOs noticed New Light's efforts and assisted with funds and guidance. Nazir represented PLWHA of Pakistan in several international conferences. He became the voice of the marginalized. Today, New Light has five satellite offices all over Pakistan, aiding people living with the HIV disease. New Light continues to struggle to get ARV medicines from across the border while it tries to ensure care without prejudice in the home country. New Light has restored dignity and self-esteem of the 'positive' people, inspiring them to become advocates for their own rights.

"We must speak out. There are thousands of 'positive' people out there walking among us, with their hearts in self-imposed exile. We have to make them feel at home again. We have to end this deportation of souls", says Nazir passionately.

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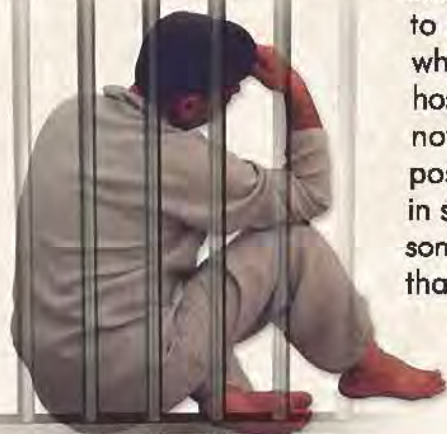
CHAINS

"They put me in shackles at the hospital. Those chains left marks on my ankles and my soul", says Qamar emotionally, when he talks about his last four days in Kuwait. A hardworking family man, Qamar, had been toiling in Kuwait for the last fifteen years. After many years of doing odd jobs for others, he finally started a business of his own last year; a computer repair shop in partnership with a friend. Life was in a groove and things were looking upbeat. Qamar used to have some difference of opinion with his partner from time to time. One day these differences escalated into a quarrel and they ended up in jail. If one knows Qamar one can tell that he is a mild mannered person, who does have the courage to stand up for his rights. In detention, the authorities took routine blood samples and then Qamar was released. He settled his differences with his partner and it was business as usual.

A week later Qamar received a call from the local hospital telling him that his blood samples from jail have gone missing and he needs to visit the hospital for a redraw. Unaware of what lay ahead, Qamar went to the hospital. To his shock and disbelief he was immediately arrested, handcuffed and later bound in shackles to a hospital bed, incarcerated in a separate room. "It was a very humiliating experience", remembers Qamar. Not knowing why it was happening to him, he got frustrated and argumentative with the hospital staff.

It was later explained to him that his tests came back positive for HIV and he will not be allowed to stay in Kuwait, any longer. "Go back to where you came from", he was told at the hospital. Four agonizing days, bound in chains, not knowing well what it means to be HIV positive, Qamar dreaded going back home in shame, dreaded that he had to tell his wife, somehow and feared the enormity of the disease that started off by taking away his freedom.

Sent to Pakistan on a one-way ticket, Qamar was not welcome in Kuwait anymore, his home away from home, where he had invested a lifetime.





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For the next year Qamar tried to learn about HIV and AIDS, knocked at many healthcare doors, in search of answers, help and support. His wife urged him to keep on going, but without a job and without guidance on HIV disease, pressures were mounting. Then Qamar reached New Light, a local NGO, for the people, by the people and of the people living with HIV/AIDS. Now he knows a lot about HIV. He figured out how the virus got into him. For the last 23 years Qamar has been going to barber shops for getting a close shave. New Light helped him understand the risks of exposure to HIV. "After joining New Light, my life has changed completely. My self-esteem and self-respect is restored. I know that I can lead a healthy life. I am not ashamed of my HIV status, anymore. My heart is at peace, and I feel I have been set free", Qamar explains. He says that he has learned a lot from the public speaking workshop that he attended at New Light. Qamar has helped in preparation of the declaration to abolish discrimination faced by the HIV positive expatriates in the Middle East and to establish a referral system between countries for post-deportation continuity of care. "I am free from the chains that bound me. I intend to help other positive people break their chains, to declare their status and have a taste of freedom. Freedom from the shackles of discrimination, fear, prejudice and ignorance."



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RED

"Do you know any man, who loves wearing a red shirt? Most men like blue. I knew such a man. He was my husband and he looked handsome in a red shirt." Fareeda talks of her soul mate. Fareeda and her husband have nine children. Their baby girl was only eleven days old when her husband left for Dubai for the last time, seven years ago. He worked there as an electrician. His visit visa had expired and he was overstaying there illegally. He was getting work and earning, so it seemed okay to stay low. One day when the youngest girl was eighteen months old, he called Fareeda long distance, saying that he was sick and his fever was not going away. Then six months later, almost five years ago, Fareeda received a call from her husband's friend, who said that the police had captured her husband and he is in jail, but not to worry, he will be out soon.

"My husband had many friends, he was full of life, and he lived for the moment. He was a kid with kids and gave his heart and soul to me when he was with me", Fareeda blushes. He was still in jail clothes, with an unshaven face and burning with a fever of 104F, when deported to Karachi. First thing he did was to call her when he got back to Pakistan. She took the first flight to Karachi. He told her, he had AIDS. He was tested in Dubai jail. Fareeda and her husband returned to their hometown and asked a local doctor to make a house call. "Think of yourself as a widow. If the government finds out they would give him a poison injection", warned the doctor. Fareeda lied to her husband saying that the doctor said that he would be fine.

"We both cried separately in private", remembers Fareeda. The next day that doctor announced in a national newspaper, that her husband has brought AIDS to the city and gave their address in the paper as well.

Everyone knew now. His brothers and sisters left him, and the neighbors shunned them. But there was a blessing in disguise with that news because positive people of New Light also read the paper and contacted the family, offering help. For the rest of his life, New Light supported the family. They brought ARV medicines and helped with many hospitalizations of her husband.

"New Light is now my extended family", says Fareeda passionately.





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"I never asked my husband how he got infected. I pray for his soul. We slept on the same bed, right till his end." Fareeda sighs looking up in the distance. It was her husband's desire to see his eldest daughter in a bridal dress. Fareeda's sister secretly gave jewelry and money for the wedding. With tears of joy in her eyes, Fareeda, talks about how her daughter is living like a princess, happily married to her sister's son. Her husband died peacefully in his sleep, although he was bedridden for many months. These days, her daughter would often call long distance and ask what her mother has cooked for dinner, "I lie every time, saying we are having a lavish dinner, but she knows I am lying, so she sobs on the phone". New Light is still helping Fareeda, with food rations and school fees for her children. "When my sons grow up, I will make sure that they dedicate their lives to the cause of people living with HIV and AIDS", Fareeda says proudly. "It was New Light people who gave the last bath to my husband's body before burial, when his own brothers would not do it. I dry up my tears for my children. I live on for my children. I miss my husband a lot. I want him to be remembered by the way he lived. I love wearing the red ribbon. It reminds me of him. Red is my favorite color now."



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SPIRAL

"No woman should be in a situation where she is forced to sell her body to buy food for her children," says Zahida. Youngest of her siblings, she was only sixteen when her aging father decided to marry her off. Zahida's beau-to-be was a handsome young man. She agreed to the marriage, but when the wedding vows were being taken Zahida realized that she was being married off to someone else. She protested but her father strangely forced her into marrying this person, whom she later found out had some psychiatric problems. Zahida's new husband did not work. He would beat her and go away for weeks to live with his sisters. Time went by. Zahida scrapped for money by doing housekeeping and cleaning jobs. Making ends meet seemed impossible. Months turned into years and Zahida became a mother of four children.

When her in-laws joined her husband in abusing her mentally and physically, she decided that enough is enough and left for her father's place, taking her kids with her. Her father became very upset. He sent her elder two children back and tried to beat some sense into her. When she refused to go back, he threw her out with her two young ones, a toddler and a breastfeeding baby. With no place to go, Zahida wandered with her children. A taxi driver gave them refuge in his house and then helped them rent a roof over their heads. Zahida searched for work and found a cleaning job but they would not allow her to bring her children to work. She was out of work very quickly. With her children hungry and her own milk drying up, she started selling her body.



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She did this for over a year and then settled down with one customer who asked her to become his mistress. He was paying her enough to get by, so she was content. Two years later this widower asked for her hand in marriage. She was in her mid-twenties and he was in his mid-fifties. She did not have to sell her body to put food on the table for her children, anymore. She was happy.

A friend from her past, who had developed symptoms of HIV disease, advised Zahida to get tested also, as she had similar symptoms. She was brought to New Light, a local NGO working for people living with HIV/AIDS. She tested positive. Zahida is very pragmatic about her illness, "I accept what I have, and I understand that I have to be careful". Her second husband is yet to be tested for HIV. After having attended the public speaking training workshop at New Light, Zahida addressed a gathering of three hundred students at a local college. She spoke on behalf of all the women who end up becoming commercial sex-workers because their families and communities have turned their backs on them.

To earn bread by selling their bodies, these women are extremely vulnerable to HIV and sexually transmitted diseases, and are less likely to seek medical advice due to fear of stigma. These shunned, ignored and marginalized women of society are prone to develop complications of stigmatizing diseases, trapped in a vicious spiral of silence, vulnerability and spreading of illnesses. "This cycle of sex-for-food can only be halted by first breaking the silence about the plight of such women," reminds Zahida.

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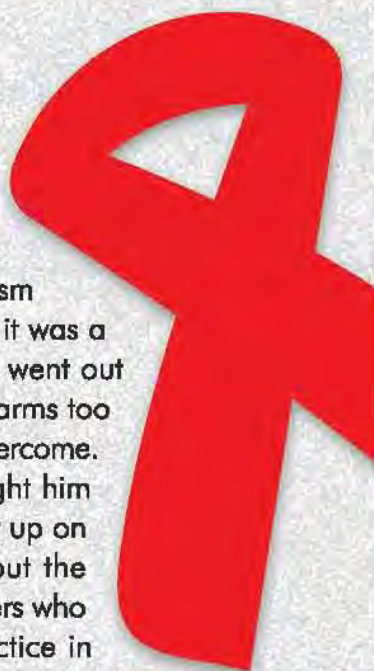
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INNINGS OF LIFE

"I have been playing cricket as far back as I can remember", says Nasir, a fifty years old tailor-master. Every Sunday, Nasir would get up at dawn and play cricket with the local boys. The teenagers would let him in the team because not only was he good but he also played with vigor and enthusiasm of a youngster. Nasir recalls that three years ago, it was a beautiful sunrise and it was his turn to bat. As he went out to the pitch and took position, he suddenly felt his arms too weak to even lift the bat. A strange weakness had overcome. He did not pass out but felt dizzy. The boys brought him home. At first he thought that age had finally crept up on him. In his heart though, he was still youthful but the weakness was overwhelming. He went to local healers who gave him injections for strength, a common practice in Pakistan. These 'strength-shots' of vitamin B12 were not helping much, and Nasir was getting weaker and weaker by the day. He could not walk over to his shop and could not even pick up tailoring scissors now, let alone a cricket bat.

After hopping from doctor to doctor and a whole battery of laboratory tests in search of answers, he came to Newlight, courtesy of a friendly neighbor. Nasir was tested for HIV and it turned out positive. With prompt treatment, he soon regained his strength and gained back his weight.

"I still do not know how I got the HIV. I have always been true to my wife and my kids are all grown up. Doctors tell me that I might have gotten it from unhygienic, injection sharing practices of local quacks. I also had jaundice six years ago", says Nasir, still trying to grapple





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with the mystery of how he got infected. He had heard little about AIDS before he tested positive for HIV. On hearing that HIV is the germ that causes AIDS, he was in disbelief and became extremely depressed. "I thought it was a death sentence", remembers Nasir.

Being a diabetic he was very careful about his diet and played cricket for exercise with religious passion. These days Nasir teaches other positive people at Newlight, on how they can protect themselves from opportunistic infections, by taking a few hygienic precautions in everyday life. "One should be meticulous in caring for one's body, just as a tailor master is very careful when cutting out a suit from a piece of cloth", advises Nasir. He has very quickly become an eloquent advocate for people living with HIV disease. He speaks with youthful enthusiasm, "You must start at home, taking your family into confidence. Once you have your family on your side, then you can tell anyone about your HIV status".

Nasir believes that prejudice against the PLWHA can be reduced in our society by spreading the word on HIV disease. "Cricket is no different from the game of life. Cricket is a team game and I intend to play a long innings of solid defense for my PLWHA team", says a defiant Nasir, who can be seen playing cricket on Sunday mornings in the park near his home. You can be on his team, if you get up early.



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Love & Faith

"God and Love of family gets me through", Shahida's eyes tell it all. The rough storms that she has endured in her life can be seen in her eyes. She talks about her two years old daughter with a twinkle in her eye and a smile that expresses nothing but a mother's pure love, brimming with hope. "They said I would live for a year. Look at me. I am still alive. I trust in God and I know God is on my side", Shahida expresses her faith.

Almost a decade ago, Shahida got married to a decorated Pakistani soldier in the UN peacekeeping force, returning from war zones of Somalia. Little did she know that her husband had the AIDS virus in his body when she married him. In no more than nine months, Shahida gave birth to a beautiful baby girl but the newborn could not thrive beyond infancy. By this time her husband had left the military service and was staying sick off and on. Shahida was expecting again. She became a mother to a healthy, cute baby boy. She made sure that her son grows into a strong boy, feeding him with the milk from her bosom. Shahida did not fully understand why her husband had started going to meetings in a local church. He took her along on one of these meetings. She learned a little about AIDS that day. Her husband was getting sicker and sicker by the day. Just when their son started walking on his own, her husband could barely walk anymore.

One Sunday he collapsed on the steps of the church. He was awfully quiet that day. "My husband was an excellent marksman", she says proudly, "He could hit a flying bird in a single shot". He kept his sidearm after leaving the Pakistan army. That fateful night Shahida woke up startled by noise, but her husband was next to her, so she went back to sleep feeling secure. The next morning the world had changed for Shahida, forever. She woke up in a pool of blood. Her husband had taken his life with the gun that saved his life many times in Somalia.





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Her in-laws filed a police report against Shahida and her ordeal began with the justice system in Pakistan. Shahida moved back to her parents' house. After several court hearings she was acquitted but another tragedy was soon to follow, as her son who was staying ill, died.

Shahida lived a life in utter loneliness. It seemed that her fate was sealed for the rest of her life, as is for most widows, in Pakistan. Life becomes a long arduous dragging wait till the end. But God had other plans for her. Some people from a local NGO, New Light, visited her at home. They invited her over and insisted that she should get tested for HIV herself. She agreed. The test came back positive. "I was not devastated by the news, I have faith in God", she says. It had been over three years since her husband died. Shahida started attending regular meetings at New Light, carrying the burden of her tragedies, alone. When Tahir saw her in the meetings, it was love at first sight. He was swept off his feet. It was clear to him that he could not live with anyone else. Everyone forbade Tahir not to marry her, she is HIV positive, but it was ordained. At first Shahida did not agree but she gave in eventually. She was taken over by love. Somehow her clouds did have a silver lining. It was her destiny to live happily ever after. "My new family gives me so much love that my sisters-in-law snatch food away from my hands and eat it, to show that they don't care if I am HIV positive; we love you just the same, they say", Shahida tells others cheerfully.



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New Light AIDS Control Society

New Light AIDS Control Society (NLACS) is a non-profit, non-political and non-religious organization. It is a pioneer group of HIV positive people in Pakistan working with more than 50 persons (females and males) and their families affected with HIV. The purpose to establish this group was to bring into light, the issues of HIV + ve people and to help them stop the dissemination of epidemic. Besides this, NLACS empowers HIV + ve people to face the challenges of life, and enhance the skills to meet the needs of the time. NLACS accommodate every infected person without any religious, social, racial and linguistic discrimination. NLACS also provide medical and psychological treatment to its HIV + ve members. NLACS is registered with the government under the Society Act 1860. New Light is also the member of Punjab AIDS Consortium, which is a collaboration of Government and Non-Government Organizations.

Family Health International

Family Health International is dedicated to improving lives, knowledge, and understanding of health worldwide. We pursue our mission through a highly diversified program of research, education, and services in family health and HIV/AIDS prevention and care. Under the Strategic Objective Grant Agreement between US Government (USG) and Islamic Republic of Pakistan, USAID is complimenting the National AIDS Control Program to promote awareness and healthy behaviors in vulnerable groups, through information, education and communication (IEC) programs regarding the risk factors for HIV/AIDS. This is the fourth focus area of the USG Health and Population Program in Pakistan.

USAID assists HIV/AIDS control interventions using support of Family Health International as management agency under IMPACT Cooperative Agreement. The IMPACT Cooperative Agreement with USAID and its interventions in Pakistan is in accordance with the successful management of USG resources on HIV/STI research, programming, monitoring and evaluation in more than 70 countries of the world by Family Health International.

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